# How many people who have had cancer experience fatigue at some point?

• 1 in 4

• 2 in 4

• 3 in 4

#### **Fatigue and NETs**

- Research shows that fatigue is the biggest challenge for people with NETs, followed by diarrhoea, sleep disturbances and pain.
  - Survey of 741 people Khan 2017

#### What is cancer related fatigue?

- Different from normal fatigue or tiredness where you feel better after you stop and rest
- Does not go away even when you rest or sleep
- Fatigue can affect all areas of your life

# Has anyone experienced fatigue related to their cancer or its treatment?

- What does cancer related fatigue feel like?
- How does fatigue affect your daily life?

"I feel like someone let the plug out somewhere and all my energy drained out"

"I wake up and I think... I've got nothing out of this sleep at all"

"It's in the limbs, but also in the head, one is listless to read a newspaper or watch television, it is total tiredness"

"It's so bad that I know I'm hungry, but I'm too tired to get up and go to the kitchen and fix it.

And if I fix it, I'm too tired when I sit back down to eat it"

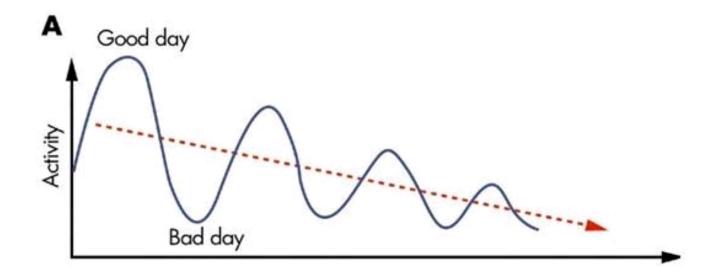
#### Factors contributing to fatigue

- Cancer treatments chemotherapy, radiotherapy, hormonal therapy, targeted therapies and surgery
- Low levels of red blood cells (anaemia)
- Other symptoms fluid retention, infection/temperature, being breathless
- Other health problems (heart problems, diabetes, being overweight, hypothyroidism, problems with your lungs, depression)
- Eating problems
- Pain
- Disturbed sleep
- Worry, anxiety or depression
- Difficulty concentrating
- Financial difficulties
- Worry about doing what needs to be done

#### Symptoms of fatigue

- Finding it hard to do routine tasks
- Tiredness / feeling of no energy does not completely go away with rest
- Problems sleeping
- Heavy legs or arms / a feeling of having no strength
- Finding it hard to concentrate or lacking motivation
- Loss of interest in things you normally enjoy
- Trouble thinking, speaking and making decisions
- Difficulty remembering things
- Feeling dizzy or light-headed
- Feeling short of breath when doing tasks
- Pain in your muscles
- Feeling more anxious or emotional than usual
- Difficulty sleeping

## **Boom and bust cycle**

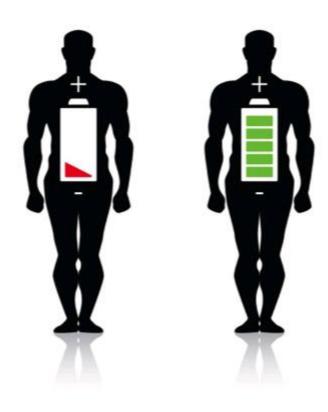


#### How do you cope with fatigue?

- Completing a fatigue diary
- •The 5 Ps
- Adapting activities to save energy
- Setting achievable goals
- Getting good quality sleep
- Physical activity
- Eating well and staying hydrated
- Relaxation
- Managing emotions
- Talking to others



# **Energy battery**



### **Prioritising**

Choosing to use your energy doing what is important to you

#### Ask yourself:

- Is the activity important to me?
- How much of my battery will this use?
   How long will it take?
- Do I need to do it? Could I do it less often?
- Is there anyone else who could do it?
- Could the task be delayed?
- Are you prioritising enjoyable activities?
   Are you prioritising physical activity?





#### **Pacing**

- Can you achieve this amount on a "bad" day?
- Can you achieve your goal through little and often?
- Do you have regular rest periods?
   E.g. between activities
- A 10 minute break each hour can help prevent fatigue and re-energise you
- Stop and rest before getting tired





### **Planning**

- Break task down into smaller chunks, e.g. mowing lawn in sections, vacuuming one room at a time, rest at a café during a walk
- Spreading task throughout the day
- Plan in some downtime / rest breaks, e.g. 10 minute breaks each hour
- Planning activities for when have more energy
   use a fatigue diary to help with this
- Develop a weekly schedule
- Concentrate on one activity at a time
- Avoid doing all tiring activities in one go
- Plan one thing you enjoy and some relaxation each day



#### **Problem solving**

- Is there an easier way to do a task?
- Are there any devices that can make the tasks easier?
   (e.g. shower chair)
- Is there anything I can buy to make tasks easier (e.g. buying pre-grated cheese / pre-chopped vegetables)?









#### **Permission**

- Be kind to yourself
- Allow for bad days (but don't try and cram everything into your good days)
- What allowances would you make for a friend?
- Instead of 'I must' and 'I should'... try 'I would like' and 'I choose to'

#### What is physical activity?

- Examples:
  - Walking
  - Jogging
  - Gardening
  - Climbing the stairs
  - Playing sports
  - Dancing
  - Swimming
  - Yoga / pilates
  - Housework / cleaning
- Government guidelines 150 minutes of moderate intensity exercise (30 mins on 5 days)

#### Why do physical activity?

- Research studies have shown that physical activity reduces fatigue from cancer.
- Physical activity is good for our mind and body.
- Physical activity can help to reduce anxiety and depression.
- Physical activity can help us to sleep better and reduces stress.
- Helps to encourage appetite.
- Initial research evidence is showing that physical activity is linked to increased survival.

# How do you feel at the moment about doing physical activity?

- Think about the things which prevent you from doing physical activity – how might you work around these?
- Also think about the things that motivate you

### Physical activity and fatigue

- Doing physical activity, even a little, can help to manage fatigue
- Too much exercise may make you feel tired, but too little can also make you feel more fatigued
- It is important to find your own level
- Try to get a balance between being active and getting rest
- Do exercise that you enjoy! Consider a group exercise programme / walking with others – lots of people enjoy the social side of physical activity and this can increase motivation
- Gradually increase the amount of physical activity you do. Begin gently, see how it feels, build up slowly.
- Set yourself achievable goals.
- If exercise is not possible, try to stay active in your daily routine.



#### Fatigue management course

- Runs at the Macmillan Centre, Southampton General Hospital
- 4 week course each session is 2 hours long
- Next course starts on the 23<sup>rd</sup> of November, 10am-12pm
- Topics covered:
  - Understanding fatigue
  - The 5 Ps
  - Goal setting
  - Physical activity
  - Eating well
  - Managing day-to-day tasks work, household etc.
  - Relaxation
  - Managing emotions
  - Getting good quality sleep
  - Managing cognitive changes
  - Communicating about fatigue

#### **Further information or support**

#### Managing fatigue:

- Macmillan information on fatigue:
   https://www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/tiredness
- 'Coping with fatigue' booklet
- Untire app

#### **Physical activity:**

- Macmillan Move More pack
- Walking for health (Ramblers and Macmillan)

https://www.walkingforhealth.org.uk/

- Pedometers
- Macmillan cancer referral exercise schemes
- Saints Foundation Exercise classes



